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ABSTRACT

Twenty-nine recommendations were compiled from ideas generated by participants at the National Conference on Self-Determination, which was called by the United States Office of Special Education and Rehabilitative Services, with over half the participants having disabilities of some kind. The participants came with different perspectives, but they shared the experiences of being kept on the margins of society, being treated as if they were not whole people, and having choices made for them. The 29 recommendations focus on the government's role, the need for self-determination as an element of public policy, improving relations between disabled and nondisabled individuals, and developing model self-determination programs. Keynote addresses are reprinted, including "Self-Determination" by Nancy Ward, "Creating a New World of Opportunity" by Robert Williams, "Self-Determination at the Community Level" by Frank Bowe, and "Self-Determination: Influencing Public Policy" by Gunnar Dybwad. Includes 10 references. (JDD)

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SELF-DETERMINATION

EC 233206

29* RECOMMENDATIONS

FROM THE CONFERENCE PARTICIPANTS

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Early in January 1989, the Office of Special Education and Rehabilitative Services invited sixty people with unusual viewpoints to meet and recommend directions the agency should take. Over half the planners have disabilities of one kind or another.* According to one OSERS official, nothing like this had ever been done before.

"Usually, it's the professional groups, the parent organizations and government agency officials who plan for people with disabilities... it's high time you, yourselves, tell us what you need!"

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*e.g., autism, deafness, blindness, epilepsy, paralysis, speechlessness, limited speech, cerebral palsy, learning disabilities, mental retardation, spinal injury—and persons who claimed that their biggest disability came from stigmas caused by psychiatric diagnostic labels.

This report has utilized the *Guidelines for Reporting and Writing About People with Disabilities* which was developed by the Research and Training Center on Independent Living (BCR/3111 Haworth, University of Kansas, Lawrence, KS 66045) and funded by the National Institute on Disability and Rehabilitation Research.

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AS THE 2 DAY MEETING BEGAN, DIFFERENT PERSPECTIVES AMONG THE PLANNERS BECAME APPARENT:

- A keynote speaker with severely limited speech asked a person using a wheelchair to sit beside him and read his typewritten address to the audience.
- In one of the five planning groups, a free-lance journalist—using a stick strapped to a welder's headband—slowly punched the keys to a computer attached to his wheelchair while his completed sentences were "voice synthesized" through a loudspeaker. Another person, using sign language, communicated the journalist's words to a government official who could not hear. The man with deafness responded in sign language which was received and voiced to the group by another person.
- A person who had been psychiatrically labeled expressed anger when others described how parents had fought successfully to get help for their children with developmental disabilities. Somehow, "parent power" meant something else in the field of mental illness.
- While almost everyone longed to be in the "mainstream" of society (with the necessary supports), four or five of the people with deafness became troubled at the thought of leaving a "highly-evolved deaf culture"—a pocket in society where communication was rich and everyone "signed."
- With determination in her voice, a woman with mental retardation talked about terrible days in an institution, how she finally became a "self-advocate" and "made it" in the community—even purchasing her own home.
- In another group, a court-appointed monitor sat with a communication board positioned on his lap. He spelled sentences with his finger on it while a person sitting beside him read the words out loud—especially for the benefit of a songwriter who was blind.

"Being pressured toward the margins of society"

"Having folks label us and treat us as if we weren't whole people"

"Having to go to programs where everyone else makes choices we should be making"

As planners shared these experiences, the clearer it became that they had the makings of a powerful coalition. From this coalescing spirit came the 29 recommendations that follow.

29 RECOMMENDATIONS IN SUMMARY

2

Advocacy organizations should enable persons with disabilities to testify for themselves at formal government hearings.

4

A program for supporting state and local self-advocacy organizations be developed.

9

Persons with disabilities be helped to compile their own oral history.*

10

A program for reshaping professional attitudes be instituted for those already working in the field.

12

School programs enable nondisabled students and those with disabilities to teach each other.

13

Sign language for persons with deafness be taught to nondisabled students in elementary schools and be included as a language course in all secondary public school language departments.

14

A formal course in human disability be included in the social studies department of public schools.

*Editor's note: Although planners were asked to make recommendations to OSERS, it became clear that some of these new thrusts fall outside the purview of this particular agency. Therefore, these recommendations should be considered by *all* government agencies at all levels. They could conceivably lead to healthier attitudes and alternatives in private sector organizations as well.

15

Persons with disabilities be provided formal courses in self-assertion.

16

Help reinforce friendships between students with and without disabilities.

17

People with disabilities be involved in in their own program planning sessions.

18

Enable persons with all kinds of disabilities to form a national coalition.

19

People who have been psychiatrically labeled be included in all coalition efforts and be allowed to represent themselves.

20

A series of model programs be funded that exemplify self-determination attitudes and practices.

21

State Protections and Advocacy Agencies hire persons with disabilities as community organizers.

22

Government should enable electronic and print media to highlight the real disability culture—its positive aspects and its soon- to-be developed oral history.

23

Bookstores set up regular sections on disability.

24

Work for universal design in technology.

25

Telecommunications devices for persons with deafness (TDD) have expanded availability and usage, and be more readily identified and understood by all citizens.

26

Innovations benefitting people with disabilities (curb cuts, television captions, accessible voter booths, security guards on subways, etc.) be advertised as helping other citizens as well.

27

Unfair financial support systems continue to be exposed when they limit the self-determination of people with disabilities.

28

Nondisabled persons be helped with perceived "inner terror" they experience in the presence of those with disabilities.

29

A national research and training center on self-determination be created.

1 The enabling of people with disabilities to determine their own futures be seen as the top priority in all government policymaking functions.

Since opportunities to choose for themselves often come last—after the choices of professionals, parents and government officials—these planners called for a change. "If we could get this priority into the heads of policymakers it would be an engine in itself," said one planner. "It would be a new mindset," said another. They recognized, however, that some persons have disabilities so severe their chances for self-determination remain small. Even so, they recommended that government shift its emphasis more in favor of letting persons with disabilities *try* to choose for themselves than to quickly and automatically let others make choices they might have been able to make slowly and haltingly for themselves.

2 Advocacy organizations should enable persons with disabilities to testify for themselves at formal government hearings.

"Maybe we aren't as fancy at talking as those who do testify," said one planner, "but it's us they're talking about . . . and if they'd just learn to slow down and listen we'd do okay." One person described the frustration he felt when he and others traveled to a Congressional hearing, only to be shunned into a side room where they listened to the hearing through loudspeakers. It was agreed by planners in another group that by allowing them to testify, the legislators would not only get fresh facts and perspectives, also they would have an excellent opportunity to change their perceptions and attitudes toward people with disabilities. One planner summed up the situation:

> Congress, in the void—because there is not a clearly articulated vision of people with disabilities—relies on professionals who are more than willing to go up there and articulate their concerns. Congress would prefer to listen to real constituencies—that is, people with real disabilities—but, in their absence, will take the advice of professionals.

3 The term *least restrictive environment* (LRE), now appearing in many federal laws and regulations doesn't go far enough.

Feeling that it didn't go far enough, planners expressed an uneasiness about letting LRE stand alone. Some argued that LRE should be replaced with *life in the community in an environment of one's own choice.* Others felt it at least needed to be changed to *least restrictive, most self determining environment.*

4 A program for supporting state and local self-advocacy organizations be developed.

Recently formed self advocacy groups show vividly that one person with a disability can sometimes help another in ways that relatives, professionals and citizens can never help. According to one planner, they can have a special way of listening to each other:

> You and I must take time to listen to those whose choices and pleas to be heard would otherwise fall on the ears of individuals who can hear, but refuse to really listen. We must stand beside those whose attempts to express themselves are frequently viewed by others as "aberrant," "offtask," "noncompliant," "inappropriate," "excessive," "challenging," "aggressive," "self-injurious," or "nonsensical." These expressions are valid attempts to communicate real wants, needs, or desires for others.

Such listening in self-advocacy organizations can help those involved to overcome bad memories, to share how each solved tough situations—even to be able to speak publicly on behalf of one another.

5 Grand proposals benefitting persons with disabilities be rated according to how well they include the concept of self-determination.

OSERS needs such a rating system in order to ensure that grantees never "wipe out our chances to choose and try to do things for ourselves."

6 A conference of persons with disabilities be called to evaluate and redirect the Rehabilitative Services Administration.

How one planner sized up the situation:

> What's wrong with rehab (RSA) is real hard to fix, because the model is wrong . . . So any attempt to fix (it) since the 1973 Act (shows) that it doesn't work. So add Independent Living. That doesn't work, so now we add Supported Employment. We keep building into it additional programs because we're dissatisfied with what the basic program does, instead of going back to the root (and saying) the model is wrong. It's a medical model. And employment is simply not a medical issue.

7 Grant review teams should include persons with disabilities.

Said one grant reviewer who is a mother of a daughter with a disability, "I am appalled at the lack of people with disabilities and family members that are part of the teams that review proposals." It was recognized, however, that some persons' disabilities will prevent such an inclusion. But even here, the decision to include or not include should be weighed in favor of persons with disabilities instead of those who serve them.

8 Internships and study fellowships be created that enable persons with disabilities to work and learn in government agencies.

This recommendation was inspired by a keynote speaker who was deaf:

> (We need) some sense of how the world works, of how public decisions get made. Again, this is not something many people with disabilities understand. For people in Washington, the concept that policies are changed and money is spent because people . . . *ask* (to have them changed and funded) is some thing you breathe in here almost like osmosis. But it is not something that many people in other parts of the country comprehend. For many of us, the powers that be are some remote body, answerable not to us but to some other authority. We shy away, many of us do, from asking for something "special," not realizing that this is simply the way things work.

9 Persons with disabilities be helped to compile their own oral history.*

Planners from different disability groups said they believe that they possess a common history which needs to be told. One planner even felt there should be a hall of fame for persons with disabilities. Another person with mental retardation—who communicated remarkably well but had a hard time reading—requested that the history be recorded by video cameras—like the oral history done by the survivors of the Holocaust. Planners felt a history developed by persons with disabilities themselves would be different from any developed by persons without disabilities.

*This *oral history* would not come only from persons who can speak. It includes the communication of past experiences from persons whose disabilities force them to remain non-vocal. In these cases, interpreters would speak on their behalf.

10 A program for reshaping professional attitudes be instituted for those already working in the field.

If government makes self-determination a top priority, many workers in the field will need to change their attitudes toward people with disabilities. Said one planner:

> I think there is a perception by (some service deliverers) that people with disabilities are not as articulate and don't know what they are talking about when they want to express their own values and wishes. One of the barriers is getting professionals to sit back, be quiet, and listen to people with disabilities without imposing their own values.

How to help make this change became a subject of discussion in all five planning groups. One group saw it as an issue in which professionals feared "the loss of power" to persons with disabilities when there needs to be "a sharing of power" between them. Another group called for programs that help persons without disabilities to "really feel what we feel." Still another felt that professionals are trapped in old textbooks that "emphasize disabilities rather than abilities."

11 Universities reshape their preservice and in-service training programs to include self-determination as a top priority.

Said one planner, "We've got to develop some more powerful approaches to professional training, that break through to a level beyond information—to real insight and sensitivity, (bringing about) a reshaping of values and ways of working." She felt OSERS should call for programs that "train teachers and human service professionals to be facilitators of empowerment." One planner called for the inclusion of people with disabilities in the training programs:

> Teacher preparation programs all over the country are run by (nondisabled) individuals. Rarely do you find individuals with disabilities in charge of these programs. Rarely do you find individuals with disabilities teaching in these programs. OSERS could very well write into the regulations that funding considerations also include whether or not individual applicants actively involve persons with disabilities in their training from the top down.

12 School programs enable nondisabled students and those with disabilities to teach each other.

According to the planners, a wide array of peer group education programs are springing up in schools across the nation. OSERS needs to identify which ones aid self-determination the most, then disseminate descriptions of these programs across the nation.

13 Sign language for persons with deafness be taught to nondisabled students in elementary schools and be included as a language course in all secondary public school language departments.

Many planners spoke of the beauty and richness that can be found in signing. To some nondisabled students, signing has become a most attractive pursuit—leading to both a satisfying skill and newfound friends. Some planners, many of them nondisabled, dreamed of a day when almost everyone in a school or a community would know how to sign.

14 A formal course in human disability be be included in the social studies department of public schools.

Planners called for a fresh approach that included their oral history—the true story of what happened to people with disabilities in the past. It should be designed to help students know what it feels like to be disabled. But most important, it should help students to "recognize and even laugh at the hidden inner terrors" they once held for people with disabilities.

15 Persons with disabilities be provided formal courses in self-assertion.

Some observations shared by planners:

- "Catch 22" choices ("You can either do this . . . or that will happen to you");
- Staff members failing to provide the array of choices nondisabled people enjoy;
- Not being allowed to even think they could be in control of their own lives;
- Oppression by staff members who feared they would lose control;
- Being forced to live up to the "perfect client" myth;
- Fear of reprisal from staff members;
- The failure to help persons find positive things that can come with a disability;
- Individual education plans that emphasize disabilities instead of abilities;
- Parental overprotection;
- Not being allowed to be resilient—to "come back" after a failure;
- The fear of not speaking out when you know something is wrong, and
- The lack of healthy role models because the literature usually describes people's failures.

The planners felt that current self-assertion training courses should be offered to persons with disabilities. The programs should use "role modeling," "interactive demonstrations," and "apprenticeship methods" instead of classroom lecture methods. Rationale: When one "works at *doing* good self-assertion" one can remember and grow in the process.

The ultimate in self-assertion was voiced by a keynote speaker who spoke on "Self-Determination at the Community Level:"

> That attitude—one of seeing the disability as personal, the problems as rather embarrassing, and the solutions as forebearance . . . what the jargon would have as "adjusting for it"—is a very, very common one among persons with disabilities. It does take a leap of logic to comprehend that society has obligations to you, that the issues are ones of human and civil rights. It takes a further stretch of imagination to realize that people with other kinds of disabilities do in fact have much in common with you, that together you can make common cause. These things are not intuitive. But that leap, that stretch, must be taken before one becomes a community activist, before one expresses self-determination at the community level . . . It requires, I think, as we saw this morning (in the first two keynote speakers), a willingness to stand up and be identified as someone who does in fact have a disability, who does have special needs . . . and that those needs should be met.

16 Help reinforce friendships between students with and without disabilities.

In planning discussions, it became clear that friendships cannot be "programmed." But OSERS needs to help schools develop a fresh alertness for them. Training, demonstration and research programs need to get people into settings where "friendships can happen." Then programmers need to develop natural ways of reinforcing these friendships.

17 People with disabilities be involved in their own program planning sessions.

Many planners presented evidence showing that some persons with disabilities are still not being invited to attend their own planning conferences. Consequently, the directions of some persons' lives are being charted by others without any input from the people themselves.

18 Enable persons with all kinds of disabilities to form a national coalition.

All planners discussed this need after a keynote speaker called on the assembly "to build bridges, to create coalitions, to bring together diverse groups to harness their energy and political power." Knowing that such a coalition can only function when it's centered on a common cause, they felt that their struggle to give the world an oral history and their constant fight against being "marginalized" could be that cause. They recognized the need to understand the exact barriers to self-determination each disability group must face. They needed to learn how to "share power" back and forth. The planners felt that if ever all of the disability groups could pull together, they would generate tremendous power—political power for bringing about social change and personal power for determining their own strengths and accomplishments.

19 People who have been psychiatrically labeled be included in all coalition efforts and be allowed to represent themselves.

Planners involved in this disability grouping described how they had been organized since 1974. And yet, it is the parents and professionals who invariably get invited to cross-disability meetings. Since they—not parents, psychiatrists and psychologists—are the ones who experience marginalizing pressures and have been denied a chance to contribute their oral history, they asked to be invited to represent themselves.

20 A series of model programs be funded that exemplify self-determination attitudes and practices.

Planners felt that they learned a skill best by *doing* it, instead of "taking courses and talking about it." OSERS needs to announce priorities and support programs that emphasize "apprenticeships," "demonstrations" and "on-task supports."

21 State Protection and Advocacy Agencies hire persons with disabilities as community organizers.

Some state protection and advocacy agencies have already carried out this plan. According to some of the planners, there have been positive results.

22 Government should enable electronic and print media to highlight the real disability culture—its positive aspects and its soon-to-be developed oral history.

Planners requested that these efforts offer a fresh understanding of people with disabilities, that they identify all the ways that belittle, demean, patronize, sensationalize and make pitiful those with disabilities today. After developing such a list, ensure that none are carried over in the new efforts. One planner suggested that we need to work conversely as well: List the ways in which the lives of people with disabilities are being better appreciated, the ways in which their lives have been enhanced, and the ways in which paths have been cleared for them to move toward increased self-assuredness.

23 Bookstores set up a regular section on disability.

Today, booksellers mingle valuable texts in a variety of sections, e.g., psychology, sociology, medicine, theology, and exceptional persons. Planners felt that a section on disability could spark a greater interest among disability groups and the public at large.

24 Work for universal design in technology.

Planners felt that manufacturers, trying to outcompete and outdesign each other, need to consider standardizing equipment for persons with disabilities. The planners felt that a better understanding of what people with disabilities face, might—just might—help them get together on behalf of these people.

25 **Telecommunication devices for persons with deafness (TDD) have expanded availability and usage, and be more readily identified and understood by all citizens.**

Interestingly, no planner other than people with deafness seemed to know what TDD stood for. Coalition power sharing should be focused on these necessary devices.

26 **Innovations benefitting people with disabilities (curb cuts, television captions, accessible voter booths, security guards on subways, etc.) be advertised as helping other citizens as well.**

When curb cuts are placed in the right spots on the street corners, they enable people using wheelchairs, mothers with children in strollers, elderly people with grocery carts and children with tricycles to cross the street more safely. At the same time they can be positioned so that persons with blindness can know where the curb is and not walk into an oncoming car. With regard to captions, the keynoter on "Self-Determination at the Community Level" made an eye-opening statement:

> Say I want to have local newscasts on television captioned. The level of understanding here is one that helps me identify "common interests"—parents of preschool children who spend Saturday mornings watching cartoons (the parents groan, but if captions were on, they'd feel a lot better about those Saturday mornings because the children would be *reading* the captions). Hispanic families anxious to learn English; new immigrants, and, of course, groups concerned about literacy (show) them how to get what they want by helping me get what I want.

27 **Unfair financial support systems continue to be exposed when they limit the self-determination of people with disabilities.**

Although one system may work well for some, it can demean and trap others. Since regulations keep some people from saving their money, the leap from dependence to independence becomes too great. One planner spoke of knowing someone who has many savings accounts in friends; names because if more than $1500 was deposited, governmental support would be wiped out.

28 **Nondisabled persons be helped with the perceived "inner terror" they experience in the presence of those with disabilities.**

Interestingly, planners with disabilities—when allowed to share unabashedly what they observed in nondisabled people—spoke openly of the fright they detected in certain individuals who are trying to relate to them. They spoke about how they longed to help these people handle such irrational fears so they could just relax and be themselves.

29 **A national research and training center on self-determination be created.**

Planners felt such a center was a must. All the issues raised could be focused at the center . . . a clearing house for the best self-determination practices . . . a repository for the oral history. It was also agreed that a research and training center that did not include people with disabilities as advisers, staff and interns would be a cruel joke.

"We have only scratched the surface in solving the problems of accessible buildings and transportation."
Planners shared one story after another that supported this view.

"The homeless are not just on the streets."
Interestingly, planners pointed out that people with disabilities who live on the street as homeless persons are also homeless when they live in institutions. Planners had an uncanny knack for discerning when a "home" is really a home and when it is merely a "holding bin."

We ought to "trash objectivity."
One planner, using his voice synthesizer, made it clear that his self-determination depended on more than people who remain "objective" with him. He felt a strong need for "subjectivity." He said he was tired of being merely an "object."

"Life without supports in the community can be grim."
A few planners with deafness expressed fears about being "mainstreamed" in community settings. One said,

> At about the age of 14 or 15, I went to a state school for the deaf. I hated it at first. My first weekend we went down to the men's room and they handed me this little mop and a bucket to clean up the urinals. I didn't want to do it. That was how I learned that the water we use in urinals is the same water we drink in our coffee. At the beginning I hated every minute of it. After I was there a while I learned to appreciate it . . . I am sure if I had remained at home during that period I probably would be bad or I would be a drunk or something of a similar nature. There are deaf people now sitting at home with parents who never bothered to learn to communicate with any fluency and they are sitting there staring at the wall, looking at their watches (and calendars), waiting for Christmas to be over so they can go back to where they are comfortable.

A rehabilitation counselor supported the speaker:

> I used to have families coming into my office with their deaf son or daughter. The parents would talk to me. The deaf person would sit in the corner, not knowing anything. There was no communication between the family member and the hearing-impaired person. They were taking about what *they* wanted for their deaf son or daughter, but what he or she wanted was not even addressed. He or she was completely out of it . . . Even though the family may have good intentions, communication is still the disability of deaf people.

The rest of the planners listened carefully to this report. They sensed what life can be like for persons with deafness in a regular home, school or community without others who can sign with them. They learned how important interpreters are as a bridge between the deaf and the hearing cultures.

On the other hand, others with deafness who lived in "mainstreamed" situations—where people knew sign language—spoke positively about life in the community.

Even so, none felt the need to divide into camps and debate the differences. Instead, all agreed that *people should be allowed to determine for themselves where they want to live.* Then everyone agreed that *life in the community without supports could be pure hell.* The recommendations reflected these conclusions.

"We need to fight for current legislation."
Although the planners' chief task was to offer recommendations to OSERS, every planning group strongly urged that Congress and the Bush Administration work hand in hand to enact or fully enforce all civil rights legislation.

"The 500th Anniversary of the New World is coming."
A keynote speaker who spoke on "Self-Determination at the Individual Level" offered government an intriguing milestone and a goal to go with it:

> In four years it will be 1992. George Bush will just be completing his term as President. We also will be celebrating the 500th Anniversary of Columbus' discovery of the New World in 1492. As we look to the future today, it is not too early to ask ourselves what kind of New World we would like to live in by 1992. Nor is it too early to begin to describe what the New World of 1992 and beyond needs to look like.
>
> We already know much of what it needs to look like. We already have touched upon much of what the future needs to look like in our discussions here. If everyone else in the country is still mystified about what George Bush means when he talks about wanting to create a gentler, kinder America, we do not seem to be mystified about it in the least. Perhaps that is because we already have a clear vision of what (it) should look like . . .
>
> In creating a New World of opportunities for Americans with severe disabilities, we must carry our message forward to President Bush, the Congress and the American people: We want our people free. We want them *well-supported* in the community where they always belonged in the first place . . .
>
> President Bush, please hear this stirring call and inspire others to hear it as well.

"We want our people free. We want them well-supported in the community where they always belonged in the first place."

Self-Determination

BY NANCY WARD

I became a self-advocate ten years ago. Being a self advocate is very important to me because my self-advocacy skills taught me how to see myself as a person with confidence and determination. I did not see myself as a person because of all the labels placed on me. People used to make fun of me all the time.

It is real hard for me not to be upset by being called retarded or dummy, names like that. They would really hurt my feelings. It is real hard for me to deal with my feelings now. I have learned that getting mad does not do any good. I have learned to talk to people about how that makes me feel. I will now share with you what determination means to me through some examples of accomplishments that my friends and I have reached.

I used to work in a sheltered workshop. To understand this story, you need to understand that the main building is separated from the contract building. My boss became ill. She had to quit. Before she did, she talked to me about applying for her job. I didn't have any confidence in myself. After talking to other people about it, I finally decided it wouldn't hurt to at least fill out an application. When I tried to fill out the application, the personnel department would not even let me fill it out. This made me upset, but I went back to work. A couple of weeks later, several staff members came to the workshop building with the new supervisor. After talking with them, I was told to train the new supervisor. Therefore, I quit and found another job.

As another example, all my life I wanted to be a nurse. I love being around people and working with them. Several years after graduating from a special education program at a public high school, I talked to a counselor at a local community college about enrolling in a nursing program. It was suggested that I take some math and science classes to prepare for taking the entrance examination for the nursing program. It took five years for me to finish these classes as I went part-time since I was supporting myself. At the time I took the entrance exam, it was discovered that I had not received a high school diploma but rather a certificate of attendance. Therefore, I would need to take the Graduate Equivalency Degree requirements prior to enrolling in a nursing program. I took the GED's five parts and received an above average score. This was very gratifying to me as it proved to myself and others that I could indeed do this work, contrary to what the local school board thought in the 1960s when the special education program did not require or have the opportunity for the students to receive a high school diploma.

Another example of how self-determination helped someone with a disability involves Jane, who has cerebral palsy. She is employed in a local workshop. Previously, she was institutionalized in Nebraska's State Developmental Center for people with mental retardation. At the institution, attendants performed all of the chores necessary in daily living so that when Jane left the institution to establish her own household, she had great difficulty doing simple tasks. Jane also has spasticity, so it was even more difficult for her to relearn eating skills. One day when Jane was eating in a workshop lunchroom, a staff member came up and asked her if she couldn't eat any better than that. These words hurt Jane's feelings so badly that she wouldn't eat in the lunchroom thereafter. After a week, she attended a self-advocacy meeting and she was able to ask for advice on what she should do to resolve the situation. It was suggested that she talk to the staff member about how her careless words had deeply wounded Jane. Jane did do this and the staff member apologized and said she hadn't realized what harm she had done. It was a situation where self-advocacy helps a person with a disability to solve a problem.

Sally is another friend of mine who had a great deal of self-determination. She had the determination to leave the relatively secure confines of a nursing home to live in the community in a group home. She had cerebral palsy and had been a patient in the nursing home for many years. It was a long road for her to follow as she first had to overcome her self-consciousness to even go out in public, such as to a movie. But she did have the determination to do this and eventually, after many small steps, such as learning how to do some things on her own and how to communicate in a socially acceptable manner, she moved to the group home. Sally flourished in the group home as she interacted with the other residents and staff members and went out with friends. Unfortunately, due to medical complications, she had to return to living in a nursing home.

However, when Sally was back in the nursing home she still participated in outside activities. She even attended a national convention (Association for Retarded Citizens). She participated in workshops, attended exhibits and the awards banquet. Though Sally used a wheelchair, she danced through the night and had a very good time. Through her determination, Sally enriched her own life, those of her friends, and those who worked with her.

As I said in the beginning, I have been a self-advocate for ten years. That is the way I became a member of People First. People First teaches people who have a disability how to speak out for themselves. It also teaches us our rights and responsibilities by showing us how to advocate for change in a positive way. People First was started by a group of people who were in an institution in 1975 in Oregon.

When I first became a self-advocate I didn't know how to direct my feelings in a positive way. I saw this commercial on Special Olympics. It made me mad because they were parading kids around the state showing how people should give money because of pity. So I yelled at the TV. My self-advocacy skills have taught me to write letters to tell people how I feel rather than to get mad about it.

Our group has done work in communities and on policymaking issues by testifying to our county commissioners on transportation, and we worked on getting a law passed in Nebraska dealing with labels like "moron, idiot, imbecile, and retarded." We were able to get the labels out of Nebraska State Statutes. People First has helped us on the individual level as well as other levels.

In closing, I would like to talk about my job at People First of Nebraska, Inc. We started working on a contract between People First and Nebraska Advocacy Services in July 1987. People First members came up with a list of names of possible members of the advisory committee. They advise me on things such as self-advocacy and policy issues. My job title is Self-Advocacy Organizer and the program under my direction is the Self-Advocacy Program. The five goals of my job are to make the ten chapters of People First stronger, work with the board of directors, start new chapters, do public education, and administration. My job is very important to me because I feel my job gives People First the potential to affect people's lives very positively.

Creating A New World of Oportunity

Expanding Choice and Self-Determination in Lives of Americans with Severe Disability by 1992 and Beyond

BY ROBERT R. WILLIAMS

Good afternoon. I am very pleased to be here and I am deeply honored to share this opportunity to address you with Frank Bowe, Gunnar Dybwad and Nancy Ward. I also would like to recognize someone who is not here: Senator Lowell Weicker.

Lowell Weicker is leaving the U.S. Senate, but he will never leave our hearts and minds. For it was Senator Weicker who, along with Madeleine Will and Justin Dart, transformed a Washington buzzword, self-determination, into a living reality for so many of us in this room and all across our Nation as well. We will never forget you, Senator, and we will continue to look to you for leadership and inspiration along the way.

As a transplanted son of Washington, DC, let me also welcome you to our Nation's Capital. Washington is a great city to live in, work, and visit. We need more individuals like you, who can shape, mold and influence what goes on here, to visit Washington more often.

I, therefore, hope that this conference will mark the beginning of a partnership among Americans with disabilities, the Congress and the new Bush Administration. Mr. President-elect, if you are as committed to fostering increased self-determination among Americans with disabilities, as I believe you are, please take note of what goes on here and plan to personally participate in other forums of this kind in the near future.

As you know, I have been asked to speak to you today on what self-determination is all about. This is no easy task. Imagine me trying to tell you about something you already know and have lived so many years.

I do not have to tell you what self-determination is all about. You and I both know what self-determination is all about. We learned it the hard way. We live it every day, and we are not about to forget what it means to each of us here today. Nor, what it could mean to our brothers and sisters who are still shunted away on the back wards of institutions, nursing homes, and other human storage bins all across our land.

We will never forget our brothers and sisters who are still locked away. Nor, the resolve we must share to set them free. This is how much self-determination as a complete way of life means to us. We want it not just for ourselves but for *all people* with disabilities. Indeed, we want it for *all people*—period. And, we want it now.

Because in this final analysis, we are *all people first.* Isn't this what the Declaration of Independence tells us: that we are *all people first and foremost ?* And, that as such we are endowed with certain inalienable rights and that among these are the right to life, liberty and the pursuit of happiness.

But, without being afforded the right and opportunity to make choices in our lives, we will never obtain full, first class American citizenship. This is why we are here today: to reassert these fundamental rights and lay claim to them as ours.

So we do not have to be told what self-determination means. We already know what it means. We already know that it is just a ten dollar word for choice. That it is just another word for freedom. We already know that self-determination is just another word for describing a life filled with rising expectations, dignity, responsibility, and opportunity. That is just another word for having the chance to live the American Dream.

Nobody has to tell us this. We know it. We understand it for ourselves, each in our own way. In fact, we understand better than most what leading a self-initiated lifestyle is all about. We try to lead one each and every day. Perhaps not always as completely or as fully as we would like or hope.

Some of us occasionally may stumble. Some of us may have to struggle more than others to make our voices heard and understood; to make our personal choices about our lives known and respected. Sometimes we succeed. Sometimes we fail. We try nonetheless. Not because we are saints or martyrs. We are neither. But, rather, because we have learned that *there is nothing else for us to do.*

We do not have to be told—you and I—what the costs and benefits of doing this are. We know what they are, we experience them every day. Indeed, we do not have to be told any of this. But, if we are not at this conference to learn about self-determination for ourselves, then, why are we here?

Why are we here? We are here to become better acquainted with one another. To grow to know, respect, and support each other as human beings who happen to share the very human attribute of being disabled.

Why are we here? We are here to recognize each individual as unique and unrepeatable. To recognize that each person here—as elsewhere—has a wide range of needs, abilities, and potential contributions to make in life.

Why are we here? We are here not to learn about the promises of self-determination from others. But, to discuss and learn about the real-life challenges and lessons of self-determination amongst ourselves. For we are the ones who know these challenges and lessons best of all.

Why are we here? We are here to enable one another. We are here to empower one another. To empower one another to go home and empower others to become more self-determining in their own lives. If anyone really wants to know, tell him or her that's why we are here.

Ella Baker, a civil rights activist of the 1960s, said it best for the great human rights struggle of her day as well as our own. Baker, who described herself as a woman who spoke "in a voice that must be heard," said in a speech, put to a song by Sweet Honey and the Rock, that:

> We who believe in freedom cannot rest.
> We who believe in freedom cannot rest until it comes . . .
> That which touches me most is that I had the chance to work with people.
> Passing on to others that which was passed on to me . . .
> Struggling myself don't mean a whole lot.
> I have come to realize that teaching others to stand and fight is the only way our struggle is going to survive.

We who believe in freedom must speak in a strong if struggling voice that must be heard. We must let it be known that we will not rest. That we will not rest until it comes to each and everyone of us. We cannot wait for freedom any longer. We will not wait for freedom any longer.

We will pass on to others what was passed on to us by teaching them to stand and fight for what should have been rightfully theirs in the first place. For Ella Baker was as right as right can be: This truly is the only way our struggle is ever going to survive.

Self-determination may start with the self. But, it cannot end there. It must not be allowed to end there. We must carry it on. We must pass it along. We must pass along to others what we have learned for ourselves by making choices in life, taking calculated risks and living by their consequences.

You and I must take the time to listen to those whose choices and pleas to be heard would otherwise fall on the ears of individuals who can hear but refuse to really listen. We must stand beside those whose attempts to express themselves are frequently viewed by others as "aberrant," "offtask," "noncompliant," "inappropriate," "excessive," "challenging," "aggressive," "self-injurious," or "nonsensical." These expressions are valid attempts to communicate real wants, needs, or desires to others.

We must stand with our brothers and sisters who are still in institutions and nursing homes throughout the land—all 176,000 plus of them (Lakin, 1988). We must help them win their freedom. And, we must help them win back their human dignity and self-respect.

To do this, we need to work together to enable individuals with even the most severe disabilities to begin to conquer and replace:

- Hopelessness with hope;
- Superimposed passivity with the dignity of risk;
- Joblessness with a real job at a real wage;
- Inaccessibility with true access;
- Speechlessness with meaningful expression;
- Confusion, anger and resentment with choice;
- Apathy with activism;
- And darkness at the end of the tunnel with light;

This much we can and must do in the name of self-determination.

But we must do more as well. We must try to learn from our temporary defeats and setbacks. As a New Year's resolution, we also should resolve not to take life's strife to heart so much. We need to learn to revel, really *revel*, in our victories no matter how small or seemingly unimportant they may appear to be.

For, as Bobby Kennedy pointed out in the most unlikeliest of places—Capetown, South Africa—in 1966:

> It is from the numberless, diverse acts of courage and belief that human history is shaped. Each time a man (or woman) stands up for an ideal, or acts to improve the lot of others, or strikes out against injustice, (he or she) sends a tiny ripple of hope, and, each crossing from a million different centers of energy and daring, these ripples will build a current which can sweep down the mightiest walls of oppression and resistance.

Today, we have it within our power to send forth not just a few ripples but an entire wellspring of hope and ideas for change all across this nation. If we choose to, we can begin to influence much of what occurs in Washington in the next four years and we must seize the opportunity to do so here and now.

In four years it will be 1992. George Bush will just be completing his term as President. We also will be celebrating the 500th Anniversary of Columbus' discovery of the New World in 1492. As we look to the future today, it is not too early to ask ourselves what kind of New World we would like to be living in by 1992. Nor, is it too early to begin to describe what that New World of 1992 and beyond needs to look like.

We already know much of what it needs to look like. We already have touched upon much of what the future needs to look like in our discussions here. If everyone else in the country is still mystified about what George Bush means when he talks about wanting to create a gentler, kinder America, we do not seem to be mystified about it in the least.

Perhaps that is because we already have a clear vision of what a kinder and gentler America would look like. Perhaps the next thing we need to do is to articulate that vision more fully for others to begin to see and help us shape. We know that in a gentler, kinder America that *all* individuals with severe disabilities will have increased opportunity to exercise more choice and control in every aspect of their lives.

"Creating a new world of opportunities for Americans with severe disabilities by 1992 must begin with putting an end to the discrimination we face today."

We know, too, that to realize this by 1992, the new President and the Congress will have to work together in ways which have not been seen in the last eight years. It will require the Bush Administration and Congress to work hand in hand to ensure the earliest possible enactment of ADA—the Americans with Disabilities Act. The new President must make ADA one of his top legislative priorities in 1989.

Creating a New World of Opportunities for Americans with severe disabilities by 1992 must begin with putting an end to the discrimination we face today. For in a truly kinder, gentler and more just America, equal opportunity must come to represent the rule of law rather than a mere exception to it. Passage of ADA will go far toward enabling our country to achieve this vital national objective.

We know what fosters and contributes to our ability to lead a life of choice and self-determination: Equal opportunity and the full protection of the law fosters and strengthens our ability in this regard. We also know what stymies self-determination: Discrimination, prejudice, and bigotry stymie its development and seriously thwart our ability to lead productive, satisfying lives.

Our message to President-elect Bush and the 101st Congress regarding ADA, therefore, must be clear and unequivocal: Endorse it in deed as well as principle. Work to secure its earliest passage. Enact it this year.

We must be equally clear, unequivocal and persistent with the incoming Administration and Congress regarding the need for comprehensive Medicaid Reform legislation to enable Americans with even the most severe disabilities to live, work, and enjoy life in the community where they have always belonged.

By the time Congress adjourned this past October, almost half of the Senate and nearly 200 members of the House had signed on as cosponsors of the Chafee, Weicker and Florio Medicaid Home and Community Quality Services Act. Congressional support for redirecting Medicaid away from institutional storage bins into individualized personal assistance and community support services, therefore, has increased phenomenally in recent years.

This is not to say that there still are not those in Congress and elsewhere who still cling to the misinformed belief that "there will always be a need for institutions." Indeed, there are still more who are misinformed in this way than certainly you or I would like. However, they are rapidly being informed otherwise every day. We must play an increasing role in this educational process as well.

But, one thing which has been sorely missing from this entire effort from its very beginning has been any kind of Presidential leadership or initiative in this area. This must change. We must make it change.

In creating a New World of Opportunities for Americans with severe disabilities, we must carry our message forward to President-elect Bush, the Congress and the American people. We want our people free. We want them well-supported in the community where they always belonged in the first place. And we "want them out, out of institutions, out of nursing homes, out of variations on these themes" (Provencal, 1988).

Australian Anne McDonald was born with severe cerebral palsy and was assumed to be mentally retarded. At age three, she was placed in St. Nicholas Hospital in Melbourne. After languishing on a back ward there for the next 15 years, McDonald summed up the brutal reality of her life and that of far too many other of our contemporaries this way:

> To be imprisoned in one's own body is dreadful. To be confined to an institution for the profoundly retarded does not crush you in the same way. It just removes all hope" (Crossley and McDonald, 1980)

In the words and deeds of Anne McDonald and countless others with severe disabilities worldwide, we can hear the makings of a clarion call to action if we choose to listen. President-elect Bush, please hear this stirring call and inspire others to listen to it as well.

If a clear Federal mandate and adequate resources are provided, there should be no need to admit anyone with severe disabilities to an institution or nursing home by 1992. This should be especially true with children. Can you think of a better way to celebrate the 500th Anniversary of the New World or to help seek an even Newer World than by achieving this vital national policy objective?

Over 176,000 Americans with severe disabilities are currently languishing in institutions and nursing homes throughout this land (Lakin, 1988). Each has a right to lay claim to a better life in the community. The time to recognize this right by enacting comprehensive Medicaid Reform legislation is now!

In 1863, Abraham Lincoln demonstrated great moral courage by abolishing the "peculiar institution" of slavery. Today, we call upon President-elect George Bush and the Congress to demonstrate similar moral courage, leadership, and vision by putting an end to the dual peculiar institutions of this century: the human warehousing and segregation of Americans with severe disabilities. We must continuously bear witness to the nation that there is not one among the 36 million of us who belongs in an institution . . . of any size, shape, color, or creed" (Provencal, 1988).

The times we are in will not stand still. We can either change the times or be changed by them. We can change our times by our activism or our apathy, by our commitment or our indifference, by our daring or our complacency. The choice is ours to make. We must make it—both for ourselves and for our brothers and sisters who are still left behind closed doors.

Thank you.

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Self-Determination at the Community Level

BY FRANK G. BOWE

Good afternoon. It is a pleasure for me to join you here at the Crystal City Marriott to talk about enhancing self-determination by individuals with disabilities at the community level. As I understand it, I will be addressing this topic for about the next half hour, after which small groups will meet to discuss recommendations.

When I think of "self-determination" I am referring to some of the attitudes and behaviors you heard about this morning. To participate in the community, as someone seeking access to and changes in the programs and activities conducted there, someone with a disability does in fact have to have reached some accommodation with the disability. So it is very true that self-determination at the individual level almost always precedes that at the community level.

I can speak from experience here. Growing up as the only person with deafness in Lewisburg, Pennsylvania, it simply never occurred to me that I could, or should, seek changes in the community. In those days, during the 1950 s and 1960 s, I saw deafness as something that was "my problem," something unique to me, something in fact "wrong" with me. The fact that I could not understand what my teachers in school were saying, what was being said on the screens of the local movie house or on the stages of local public theatres, was just the way it was.

That attitude—one of seeing the disability as personal, the problems as rather embarrassing, and the solutions as forebearance or suffering through, what the jargon would have as "adjusting to it"—is a very, very common one among persons with disabilities. It does take a leap of logic to comprehend that society has obligations to you, that the issues are ones of human and civil rights. It takes a further stretch of imagination to realize that people with other kinds of disabilities do in fact have much in common with you, that together you can make common cause. These things are not intuitive. But that leap, that stretch must be taken before one becomes a community activist, before one expresses self-determination at the community level.

When I think about self-determination in the community, what springs most rapidly to my mind is implementing and enforcing what is already supposed to be there. I am thinking of curb cuts and ramps, of interpreters and readers, of group homes and accessible voting booths. I am not thinking here of influencing social policy, of stirring up social ferment to change the rules of the game. That is something that requires yet another level of awareness, one we will look at tomorrow morning.

To do these things—to find out what is supposed to be out there, to determine whether it is in fact there, to identify who is supposed to put it there, to pinpoint what is keeping it from getting done, and to decide which strategies and tactics are most likely to be effective in getting it done—requires several things, some personal, others social.

It requires, I think, as we saw this morning, a willingness to stand up and be identified as someone who does in fact have a disability, who does have special needs. That, for many people, is not an easy thing to do. After my mother had a stroke a few years ago, and began using a wheelchair, she began going through some of the stages I went through many decades ago. At first, she withdrew into her home, not wanting to come out for fear of embarrassment. Later, realizing that people would not think less of her just because she used a chair, she still put off ventures into the community, saying they were no longer convenient, that they exhausted her. Even to this day, some five years after the stroke, she does not accept as reasonable that she request curb cuts in the streets between her home and the downtown shopping area. Those curb cuts will not be made unless and until she asks for them, and she does understand that, but still she does not act.

The members of ADAPT, the advocacy organization now mobilizing in cities across the country for accessible mass transit, exemplify for me that willingness to state, factually and without embarrassment, that there are special needs and that those needs should be met. We may disagree with the tactics chosen by ADAPT, notably the use of wheelchairs to block rush-hour traffic in downtown areas, but the fact is that ADAPT members have crossed the threshold that still restrains my mother in Lewisburg.

It requires, then, some sense of how the world works, of how public decisions get made. Again, this is not something many people with disabilities understand. For people in Washington, the concept that policies are changed and money is spent because people—in ones, twos, dozens, hundreds, thousands even—*ask*, is something you breathe in here, almost like osmosis. But it is not something that many people with disabilities in other parts of the country comprehend. For many of us, the powers-that-be are some remote body, answerable not to us but to some other authority. We shy away, many of us do, from asking for something "special," not realizing that this is simply the way things work. The fact that the general interest is little more than many special interests. The fact is also that what helps me as someone with a disability often helps someone else, someone who has no disability. I have to know those things, and to act on them. Self-determination at the community level requires an individual with a disability to know enough about electoral and appointive politics to see where the levers are and who can pull them.

The students at Gallaudet University demonstrated such an awareness last March when they showed considerable sophistication in getting the Congress, the media, and the civil rights groups to join them in their efforts to force a recalcitrant board of trustees to hire a President with deafness for the University. The board's choice, Dr. Elizabeth Ann Zinser of North Carolina, did in fact state that she withdrew as Gallaudet President because of that external support, what she said was a "civil rights moment in history" for people with deafness, and not because of the students' own rebellion. By the time she took that action, virtually everyone who had been heard from had sided with the students. The only ones still publicly supporting Zinser were the trustees.

It also requires an understanding of how to build bridges, to create coalitions, to bring together diverse groups to harness their energy and political power. Coalitions form around common interests. Self-determination may seem at conflict with community determination, but really it is part and parcel of the same thing. To the extent that I as an individual with a disability can make you see that you want what I want, to that extent I have increased my base, strengthened my hand, and expanded my options. Say I want to have local newscasts on television captioned. The level of understanding here is one that helps me identify "common interests"—parents of preschool children who spend Saturday mornings watching cartoons (the parents groan, but if captions were on, they'd feel a lot better about those Saturday mornings because the children would be *reading* the captions); Hispanic families anxious to learn English; new immigrants; and, of course, groups concerned about literacy, and so forth—and then to canvass each group, showing them how they can get what they want by helping me get what I want. That's fairly sophisticated politics, but it is what is needed for self-determination at the community level.

We as people with disabilities need to recognize that some of those common interests are shared by professionals, parents, and others who do not have disabilities. We need to work with them, not against them. We need to take full advantage of independent living centers (ILCs) of state protection and advocacy (P&A) systems, of parent-based groups like the Association for Retarded Citizens (ARC) chapters and others in order to pull together enough common interests so that what began as our own "special interest" gradually takes on the shape and appearance, indeed the reality, of the general interest.

If what I've said has any basis in reality, and some 15 years of experience organizing at the community, state and national levels tells me that it probably does, it suggests that in your small groups you concentrate on how to, first, help people with disabilities to openly and unabashedly acknowledge their needs; second, teach people with disabilities how to influence the decision-making process in public and private organizations; and third, guide people with disabilities in identifying allies with whom they can make common cause.

Thank you—and good luck.

Self-Determination:
Influencing Public Policy

BY GUNNAR DYBWAD

In most books and articles on rehabilitation trends in the United States, the onset of the independent living movement is given as the early 1970s (Dajong, 1983), yet history reads quite differently. It was in 1957 that Representative Carl Elliott of Alabama, Chair of the Special Education Sub-Committee of the House Committee on Education and Labor, introduced HR 69-81 which provided for federal funds to the states for the development of independent living services. This legislative proposal came about in response to a resolution adopted in October of 1956 by the Delegate Assembly of the National Rehabilitation Association. E.B. Whitton, the Executive Director of NRA, welcomed this legislative development enthusiastically in an editorial in the May/August 1957 issue of the *Journal of Rehabilitation* which ended as follows:

> We believe the time will come when this decision, that state-federal support should be made available for independent living rehabilitation services, will be regarded as the initiation of another great forward movement in rehabilitation and in the evolution of the Association toward becoming the organization to which all rehabilitation people look for leadership.

Unfortunately, he spoke too soon. Neither this bill nor a similar one, HR 3756, introduced in 1961 which also proposed federal funds for independent living provisions, gained a favorable vote in Congress. It hardly needs emphasizing how much further ahead we would be if federal financing for independent living services would have been available 15 years earlier, and at that, in a period with much more generous financing. Why do I bring these old potatoes to your attention? Because very obviously there had not been enough effort or enough manpower to influence the public policy in question.

The field of rehabilitation in those days was firmly in professional hands. It had been only a few years earlier that the National Rehabilitation Association had voted to admit other than professionals to membership. Rehabilitation was as conservative as other human services—the recipients of service had the identity of clients—petitioners, rather than valued collaborators in a common enterprise.

Need I say more than to remind you of what happened to Ed Roberts in those very days in California, when he was downgraded as "not feasible" by those who should have served him? But Ed Roberts had gained for himself a different identity, not that of a dependent client but of a citizen. His self-concept was clear—he did not allow the rehabilitation professionals to downgrade him, and with singular self-determination, he forged ahead, his severe physical impairment not withstanding, and eventually created our country's first center for independent living. In due course, he was appointed by Governor Jerry Brown to be the head of the State Rehabilitation Department that had cast him aside as "not feasible."

The question suggests itself: How was it possible that in a progressive state like California repeated requests for services and equipment from a so obviously bright and alert person as Ed Roberts elicited such negative responses from the rehabilitation authorities? Gerben DaJong (1983), in exploring the reasons why persons with disabilities in general encounter as many obstacles if not outright rejection, sees the cause in the broad general scene. In an article on "Physical Disability and Public Policy," he wrote:

> The ultimate and most pervasive of environmental barriers are the attitudinal ones, particularly the view that disabled people are helpless, pathetic victims, deserving charitable intervention. There is now more than enough experience to indicate that disabled people can, with appropriate environmental support, lead full and independent lives. Without the removal of attitudinal barriers, the disability legislation of the past decade will not realize its full promise.

To achieve such a basic change in attitude will take precisely what our session today is all about. It will take the effective, long-range influencing of public policy on all levels of government, legislative, executive, and judicial—and the action has to come from the persons with disabilities themselves.

Let me clarify this with some facts from my own experience in the public policy field. On a consultative basis, I had been instrumental in 1968 in suggesting to a committee of the Pennsylvania Association for Retarded Citizens, deeply concerned about the refusal of schools to admit children with mental retardation, and more yet, about the intolerable neglect and cruelty in state institutions, that since they had over several years tried in vain to get remedial action from the legislature and administration, the time had come to go to court. The committee was strongly in agreement with their recommendation, but when the matter was brought to the full board of the Association, there was strong resistance. After all, it was said, how could the Association dare to sue the Secretary of Welfare or the head of the State Education Department, on whose good will they had to count? In other words, the members of the Association's board saw themselves as clients, depending on the bounty of these departments and their bureaucrats. With such a self-imposed identity, with such a negative self-concept, how could they confront the authorities on whose benevolence they believed they and their children depended?

It took six months before the committee chair, in a very ingenious way (which lack of time prevents me from presenting) convinced the board members that their parental role, their responsibility toward their children, by far outweighed their relationship with government.

Thus, they came to see themselves in a different light. Their self-concept changed and their resulting self-determination for them to initiate a landmark lawsuit that resulted in establishing by judicial decree a massive advance in educational policy: No child may be excluded from public education for reasons of handicap, no matter how severe. Three years later, Congress passed P.L. 94-142, the Education of All Handicapped Children Act. It was a singular victory, but unfortunately, not a lasting one. News from throughout the country continues to show that the implementation of this law on the local level is still seriously lagging. Almost everywhere there has been and there still is a need for strong local effort to influence public policy in line with the promise of P.L. 94-142.

The same situation prevails, of course, regarding the keystones to the rights of persons with disability, Section 504 of the 1973 Rehabilitation Amendment and all subsequent amendments.

But how is an effective action program to be initiated and maintained? Rita Varela (1983), writing on "Organizing Disabled People for Political Action," points up that the political realities in our various states differ so very much in terms of local conditions and local leadership that any national campaign must depend on dispersed indigenous leadership to maintain its initial impact. Obviously this necessitates continuing efforts in recruitment and training to gain such leadership. While we have made great progress in using computer programs in teaching technological aspects of work routines, how does one go about helping persons develop a more positive self-concept, leading to a stronger self-determination and to empowerment? And whence comes this concept of empowerment? I never heard this term used during my years of work in the human services.

In the 1930s, 40s and 50s, not surprisingly, one cannot pinpoint one specific source, but it emanated in part from the struggle in the 1960s around the Model Cities programs and the efforts to give inner city populations a voice in the councils which directed their fates. Unfortunately, that improvement turned out to be an empty promise as Stephen Rose (1972) documents in his monograph, *The Betrayal of the Poor: The Transformation of Community Action.* One of the many other examples from that period was the initiative of a group who organized themselves as Mothers on Welfare and who, in the State of Massachusetts, confronted the Department of Welfare, exposing its inadequate and confusing practices. Among other successful actions they empowered themselves to write a manual on procedures which the Department had to admit was long overdue.

Mothers on Welfare made themselves heard and, notwithstanding their aggressive, confrontational stance, were for the time being accepted as partners by the Department. However, the group, organizationally isolated, lacked the resources to maintain the power it had gained, and slowly faded away.

So what is empowerment?

As one writer states: Empowerment takes on a different form in different poeple and contexts (Rappaport, 1984). Others argue that empowerment is in most instances not a single act but a process. It may start on a rather modest basis, but as Douglas Biklen (1988) pointed out in his comments in the *TASH Newsletter* (of the Association for Persons with Severe Handicaps), "A wonderful side effect of this empowerment is that it nurtures itself and grows. It produces a system based on self-determination and productivity, i.e., the power of an individual to fully develop his or her potential for a regular life with regular choices. In other words, the empowerment of the advocate results in the empowerment of the consumer—a very simple formula."

I do agree with Biklen but with a very important proviso: Once acquired or activated, the empowerment must be maintained by power sharing, whether through a coalition or other support groups, by exchange or accommodation, or else it will dissipate sooner or later.

Empowerment means that someone or some group or organization acquires or activates power it has not exercised before. But it takes more than having an authority bestowing power—there must be a readiness to take on what may well be not so much a privilege but a burden.

Empowerment may be directed at staff members who need this and are organizing to get it from the agency, or it may be directed at the clients, or both groups may work separately or together toward empowerment.

In an article in the Spring of 1988 issue of *Social Policy*, entitled "Empowering the Homeless," Michael Fabricant (1988) reports on several smaller voluntary agencies which all have recognized that only by designing a process of empowerment of homeless people who have come for help, can a constructive relationship develop between the client, the social worker, and the agency itself.

Homelessness is such an extreme situation that the usual social service agency approach will not work. Most importantly, the physical surroundings, the demeaning impersonal routines (brought about by severe overcrowding in the shelters), creating most serious violations of health and housing codes, make clear to the applicants that they are at the bottom of the human scale, powerless and of no use to society. Thus these agencies on which Michael Fabricant reports set out on a plan of empowerment, on seeking in every way to provide for their clients some choices, and to move away as far as possible from the traditional social service practice of encouraging so-called objectivity by keeping the seekers of aid at a distance. The homeless people in turn come to feel a greater understanding of their own strength, develop a sense of self-determination and empowerment which results in a greater capacity to challenge the conditions of their life.

It is important to note that the agencies involved in this study were not large, bureaucratic entities, but small non-governmental units where such radical alteration of routines was feasible. A pervasive question remains: Can our ruling bureaucracies, can our legislative bodies comprehend and support such a radical departure from the traditional pattern of service provision?

A significant new venture in the arena of empowerment has been undertaken by the Governor's Planning Council on Developmental Disabilities in Minnesota, under the title "Partners in Policymaking." Observing the marked decline in active participation by parents of children with developmental disabilities in public affairs, especially in planning and in legislation, the Council has established a rather intensive training program for citizens, including parents of children with developmental disabilities and also some self-advocates. It aims at giving them an understanding of today's issues and of ways to acquire a power base from which to advocate. Participants are reimbursed for their expenses but must obligate themselves to attend all the sessions and training events. The expectation is that after the course, many of these parents having sought empowerment will play a role in improving services, in pushing for legislation and in locating and pursuing instances of inadequate attention to the special needs of people with disabilities.

The results so far are encouraging and I think you will agree that among deprived, disenfranchised groups in our country, the residents of mental retardation institutions are near the bottom. But even from there comes new strength, a self-determination, a new voice of self-generated improvement. Just a few weeks ago, a group of residents of the Southbury Training School in Connecticut asked some of their friends in the community to arrange for a press conference. This conference was held at the institution and most of the larger Connecticut newspapers carried an account, some on the front page, about these self-empowered institutional residents appealing to the public for justice and the termination of their institutional confinement.

So far my comments have dealt with empowerment directed at social action. But the empowerment of individuals toward leading a richer life, toward greater self-fulfillment certainly is for many of us at least of equal concern.

One of the oldest stratagems in the disability movement has been the one-to-one approach to parents—whether it was called Pilot Parents, Parent-to-Parent, or as in France, L'Action Interfamilial—Interfamily Action. In Massachusetts, I had encountered already in 1958 a well-functioning program called Parent Resource Persons. These programs remain effective even where there are relatively full service programs because they can give parents who have never had or sought outside help the courage to do so.

As the disability movement matured, the focus included more and more the persons with disability themselves, highlighting personal adjustment struggles often by far exceeding those of parents. Into this challenging area has come this very month a beacon of light, a new book by our friends, Robert and Martha Perske. Its title tells it all: *Circles of Friends: Persons with Disabilities and Their Friends Enrich the Lives of One Another.* Essentially, it is a series of vignettes showing how human beings are being helped to develop or regain the power they need to cope. It is a gripping, realistic book, but like all of the works of Bob and Martha, there is a beauty and serenity about it.

For our discussion today, the book has a specified meaning because one of its vignettes shows how Judith Snow, whom I have known from my work with the G. Allen Roeher Institute in Toronto for a number of years, at one point no longer could cope alone with her existence in a wheelchair with only one thumb functioning. She had been active in education and the human services, but problems became too much for her and she virtually collapsed. At that point, a circle of friends formed around her—it is a gripping story to read—and now she is back at work and both the Canadian Government and the Canadian Association for Community Living value her as a leading expert on the political and social situation of persons with disabilities.

Again we need to recognize that self-determination as much as empowerment cannot continue indefinitely without strong, positive reinforcement, a recharging of the batteries, so to speak. This crucial point needs to be aimed toward the long-range planning of social action such as the implementation of significant, broad legislative advances.

Circle of friends is one figure of speech. Bridge building, or building community are others. From Communitas, Inc., a Connecticut group, has just come a contribution entitled *What are we learning about bridge building—a summary of dialogue between people seeking to build community for people with disabilities.* It is more of a how-to-do book, also focusing on how to enable individuals with disabilities to gain the power to cope with life.

Throughout my long friendship with Robert Perske, he has time and again redirected my thinking into new and innovative channels and he does so with formulations which at first sound so very simple—until you begin to fully understand their significance. Let me then quote from his concluding words in *Circles of Friends*:

> *As people take to each other, persons with disabilities have been able to contribute their own unique richness to their friends and to the surrounding neighborhoods as well. Therefore, I believe that friendships with people who have disabilities can provide an explosion of fresh values and directions which this confused, misdirected world needs now as never before.*

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APPENDIX
THE CONFERENCE SCHEDULE

Monday, January 9, 1989

9:00am—9:30am
Welcome and Opening Remarks: Michael Ward and Madeleine Will

Introductions: Patricia McGill Smith

Conference Logistics: Colleen Wieck

Discussion Group Orientation: Fran Smith and Edward V. Roberts

9:30am—10:30 am
Keynote Address: *Self-Determination at the Individual Level*
Nancy Ward, Keynote with Mary Jane Owen, Introduction

Robert R. Williams, Keynote with Robert Perske, Introduction
and Christopher Palames, Reader

10:45 am—12:45pm
Five Concurrent Groups Sessions: *Discussion and Drafting of Recommendations to Increase Self-Determination at the Individual Level*

2:15 pm—3:00 pm
Keynote Address: Self-Determination at the Community Level
Frank G. Bowe, Keynote with Richard Johnson, Introduction

3:00 pm —5:00 pm
Five Concurrent Group Sessions: *Discussion and Drafting of Recommendations to Increase Self-Determination at the Community Level*

Tuesday, January 10, 1989

8:45 am—10:00 am
Keynote Address: *Self-Determination: Influencing Public Policy*
Gunnar Dybwad, Keynote, with Colleen Wieck, Introduction

10:00 am—1:00 pm
Five Concurrent Group Sessions: *Discussion and Drafting Recommendations on How to Increase Self-Determination in the Influencing of Public Policy*

1:30 pm—3:30 pm
Small Groups Report in Plenary Session

3:30 pm
Adjournment

CONFERENCE COORDINATION

Conference Committee:
Michael Ward, Chair
Susan Daniels
Shirley Dean
Naomi Karp
Christopher Palames
Mary Jane Owen
Patricia McGill Smith
Nancy Ward
Richard Johnson

Conference Facilitators:
Fran Smith
Edward V. Roberts

Discussion Group Leaders:
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Christopher Palames
Michael Ward
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